

## **CONSUMER INFORMATION, COMMUNICATION & INVOLVEMENT FINDINGS AND RECOMMENDATIONS**

### ***Introduction***

Rapid changes in the health care delivery system have resulted in elevation of the importance of consumer information and involvement. The potential benefits of managed care, namely lower costs, higher quality of care and greater consumer satisfaction will be realized only in a system characterized by active and meaningful consumer participation.

This paper addresses the interrelated issues of consumer information and involvement in the health care system. A brief section on communication of consumer information is also included to highlight the importance of the format in which information is made available or presented to consumers. The paper is structured in two parts: the first will present background, principles and recommendations for improving managed care through better and more accessible consumer information and the second will do the same for effective consumer involvement.

### ***Consumer Information***

The historical physician-patient relationship, which was characterized by the professional authority of the physician and a relationship based upon trust, has been altered by the introduction of managed care. In an environment in which a third party can intervene, the patient needs access to and an explanation of information relevant to the decision about appropriate treatment. In addition, with the health care delivery system's shift from a focus on treatment to prevention, consumers need knowledge about health promotion activities in general and about their own health status. These shifts imply a need for health care information, communicated in an effective manner.

In managed care, the consumer becomes an advocate for him or herself and a "partner" in his/her care. In this new role, the consumer needs access to a range of information on plans and providers. While a great deal of information is provided to consumers by health plans and/or submitted by health plans to regulatory authorities, the extent to which consumers are able to use this information to compare plans and make effective decisions is unclear. In addition, much information which consumers need to effectively participate in the health care choices remains unavailable to them.

California consumers have long voiced concerns about the availability of information on managed care organizations collected and disseminated by state oversight agencies. In a 1992 study, the California Auditor General found that the DOC had been lax about maintaining its public access

files, responding to complaints and performing required monitoring visits. In a 1996 report, Consumers Union documented the difficulties consumers have in obtaining information from the Department of Corporations.<sup>2</sup> This report noted that although the Knox-Keene Act requires the DOC to educate and inform consumers about HMOs,<sup>3</sup> DOC provides consumers with little information to assist them in choosing or using health plans.

Consumer advocacy groups and private organizations use a combination of government-generated and market-generated information to provide consumers with health care system information and various types of “rankings,” generally at the health plan level. A broad range of resources have also been developed to educate consumers on clinical issues and help them respond to their role in the managed care system. A great deal of information that was until recently considered “professional” has been brought into the public domain. Information designed to help consumers access information and educate themselves about a broad range of clinical issues is provided in print and via media such as videotapes and Internet sites. Examples of these initiatives range from “ask the doctor” email forums to consumer-focused clinical education and decisionmaking tools to patient advice/peer groups for people with specific conditions and diseases.

### ***Communication of Consumer Information***

While plans, providers and independent monitoring organizations currently collect a great deal of information on performance of health care organizations, this information is often not translated into measures that are of interest to consumers. In addition, lack of standardization of information collection and dissemination has made it difficult for purchasers, plans and advocacy groups to provide consumers with useful, relevant information for plan and provider selection.

Recent studies reveal significant problems in communication of important managed care information to consumers. The vast majority of consumers do not currently understand even the fundamental operations of the plan in which they are enrolled (e.g. how managed care plans differ from traditional indemnity insurance<sup>4</sup>). In addition, a recent study of the “readability” of health insurance literature and contracts found that the average document was written at a reading level of third/fourth year college to first/second year graduate school.<sup>5</sup> The results of the 1992 Adult Literacy Survey conducted by the US Department of Education indicated that writing directed at the “general public” should be at the seventh or eighth grade level.<sup>6</sup>

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<sup>1</sup> Report by the Auditor General of California, *The Department of Corporations Can Improve Management of Medical Surveys and Consumer Complaints in its Health Care Service Plan Division*, R-115, May 1992.

<sup>2</sup> Hamburger E, “A Shot in the Dark: The Department of Corporations Fails in its Job to Educate and Inform Consumers about Choosing an HMO,” Consumers Union of the US, Inc., West Coast Regional Office, April, 1996.

<sup>3</sup> California Health and Safety Code 1342(b) (West 1996).

<sup>4</sup> Isaacs, SL, “Consumers’ Information Needs: Results of a National Survey,” *Health Affairs* Winter 1996.

<sup>5</sup> Hochhauser M, letter to the Editor *Health Affairs* September/October 1997, p 220.

<sup>6</sup> Kirsch IS et al., “Adult Literacy in America, A First Look at the Results of the National Adult Literacy Survey,” Washington, US Department of Education, 1993.

Communication of plan features and requirements in terms and language accessible to enrolled consumers will enhance both efficiency of operations and consumer satisfaction with managed care plans. Employer coalitions, such as PBGH, have made the most extensive and successful efforts at providing such information to date.

### ***Principles for Consumer Information***

The following principles should guide development of recommendations regarding consumer information in health care:

1. Full and accurate disclosure of appropriate information can serve to foster best practices.
2. Consumers' ability to understand differences in quality among health plans and providers is critically important to efficient functioning of the health care delivery system.
3. Consumers' ability to choose among and effectively use health plans and providers is critically important to efficient functioning of the health care delivery system.
4. Consumers should have unbiased, standardized information about health plans, medical groups and physicians.
5. Dissemination of accurate, useful information will enhance consumer trust in the managed care system and drive quality improvement by plans and providers.

### ***Recommendations for Consumer Information***

1. The state agency charged with oversight of managed care (currently the DOC) should issue a request for proposals for annual production of a consumer-focused, educational booklet on the managed care system in California.

This publication should be produced by an organization with experience in health benefits purchasing and communication. It should be produced at a simple enough reading level and in sufficient formats and languages so that it is useful to all consumers. The publication should be tested and evaluated with consumers to determine that it is understood by and useful to consumers. When data support that the publication is useful and understood, a dissemination plan should be developed to ensure that it is distributed to all managed care consumers.

2. In addition to the recommendation in the Task Force paper on Standardizing Health Insurance Contracts that the state agency charged with oversight of managed care (currently the DOC) convene a working group to develop a standard outline and definitions of terminology for the Evidence of Coverage (EOC) and other plan documents, we recommend that the above mentioned agency:

Create and update at least annually a "standard product description" in a format to facilitate direct comparison of plans by consumers, designed with input from stakeholders, in as non-political a process as possible. The CalPERS format could be considered as a model for this document. The DOC should require plans to use the standard format to present information about any product they offer.

This standard benefit characteristics document should include a statement on how drug formulary decisions are made; should describe key elements of the plan's grievance procedure (including a description of any arbitration processes); should include "exit polling" information on number disenrolling and primary reasons for disenrollment; and should offer, for each plan or medical group with which the plan contracts, a brief but specific description of the referral and authorization process, and the process through which medical decisions are made. The DOC should make these descriptions available to consumers upon request free of charge and should make this information available on the Internet.

3. Plans should be required to submit to the agency charged with oversight of managed care approximately 10 major health conditions or illnesses requiring referrals to specialty centers or centers of excellence (e.g. bone marrow transplants, coronary artery bypass grafts). Data should be reported on an annual basis for the prior year, and should include, for each condition or procedure, where and from whom the patient received care, and how many of the procedure in question the center to which the patient was sent performed in that year.
4. Upon request by an enrollee, all plans and medical groups should be required to provide copies of any written treatment guidelines or authorization criteria.
5. The agency charged with oversight of managed care (currently DOC) should cause to be created a "Super Directory" of physicians and other primary care providers (e.g. advanced practice nurses), hospitals, clinics and medical groups participating in health plans, indicating which plans or groups they contract with. The purpose of this directory is to ensure that consumers receive accurate information on whether a particular provider or group will be available to him/her as a member of the plan. Primary care physicians' entries should indicate whether or not they are accepting new patients and to what facilities or specialists their patients may be referred. This information should be made available to all consumers at the time of enrollment and renewal and to individual consumers at any time upon request.

Plans should be required to update this information on the Internet continuously, and to update and make it available in print at specified locations at least quarterly. This information could then be made available to consumers through employee benefits offices, libraries and consumer advocacy and assistance organizations. Plans should be required, upon member or potential enrollee request by telephone to provide "Super Directory" information, e.g. a) to indicate whether a particular physician or provider group is a member of the plan's network, and whether each participating primary care physician is accepting new patients and/or b) to provide a list of specialists of a certain type in a certain geographic area.

6. The state agency charged with oversight of managed care organization's (currently DOC's) report on grievances should be expanded to include more detailed and meaningful information on grievances. The DOC currently provides information on complaints (in DOC terminology "requests for assistance" or RFAs) filed with the Department in writing, after the plan has had 60 days to resolve the problem. Current information provided by DOC includes a report on the number of complaints by type of complaint and plan. We recommend that the report additionally include an indication of the severity and urgency (as defined by threat to life and health) of the complaint and whether and what action was taken by the plan and/or DOC in response to the complaint. This additional information is critical if consumers are to be able to use the complaint information in choosing a plan. This recommendation would provide an

improvement in disclosure to consumers using information that is already available to DOC. (See the Task Force paper on Dispute Resolution for additional recommendations on reporting and disclosure of grievance information.)

7. The state agency charged with oversight of managed care should support and fund, to the extent possible in collaboration with private sector efforts, gathering of additional patient satisfaction and quality data at the provider group level as well as the plan level. The PBGH/Medical Quality Commission “Physician Value Check” could be considered as a model for medical groups, and the FACCT framework is one example of a good model for collection of data at the plan level.
8. Employers that pay a portion of employees’ health benefits coverage should include such payments as a separate line item on employee pay stubs to begin to increase awareness that dollars spent on health benefits are a part of employees’ total compensation. Employers should be encouraged to collect information from their employees on their experiences and problems with health plans and medical groups so that this information can be used in the plan negotiation process.
9. Please note that The Task Force paper on Financial Incentives for Physicians in Managed Care Plans presents several specific recommendations regarding disclosure of information about financial arrangements and payment mechanisms to consumers.

### ***Consumer Involvement***

Formal consumer involvement mechanisms are necessary to ensure that consumers have a “voice” in shaping the health delivery system and their role in it. While most health plans have some member involvement mechanisms in place, few have implemented extensive programs for consumer feedback that have proven effective. Most consumer activity has focused on issues such as review of marketing materials and grievance procedure policy development. Most plans acknowledge that while they attempt to obtain member input on print materials, they do very little formal testing of educational and marketing materials to determine whether consumers understand or can effectively use them.

Ombuds programs, member advisory committees and tools such as the “Consumer Feedback Loop”<sup>7</sup> have been developed to allow all parties in the system to obtain and benefit from the input of members. (An example of information gathered in a representative Consumer Feedback Loop is included as an attachment to this report.) While purchasers, plans, providers and consumers have all recognized the benefits of such involvement mechanisms, because the spirit of the Knox-Keene provisions for consumer information and involvement are not being achieved, strong incentives will likely be necessary if plans and providers are to seek active participation of members in formulation of policies, marketing materials, product design and plan operations and evaluation.

Attempts to improve upon the current level and nature of consumer information and involvement should be driven by an understanding of consumer values. Advocates and studies have characterized seven consumer values that relate to the health care delivery system<sup>8</sup>

*Affordability:* Quality health care at a reasonable price. Members most often cite affordability as their primary purchasing criterion and express a fear of losing access to quality care because costs are too high for their employers or themselves.

*Choice:* Consumers are allowed to choose their health care providers, ideally at each of three levels: the plan, the medical group and the physician. Consumers often feel that they do not have the information they need to make informed choices.

*Accountability:* Consumers enrolled in a plan are presented with clearly identified agents and processes through which to resolve problems. Members are concerned that accountable organization resolves problems in a pre-stated and timely manner.

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<sup>7</sup> The Consumer Feedback Loop, a tool developed by California Health Decisions, is a model for improving health care quality that involves patients, providers, purchasers and health plans in a consumer-driven process of research, solutions, change and evaluation. The Consumer Feedback Loop is a process that fosters cooperative efforts towards quality improvement. Its goal is to shape change in a health care delivery system or structure around the best interests of the consumer.

<sup>8</sup> These values have been developed by California Health Decisions, and are described in more detail in its “Condition Critical Project” report.

*Personal Responsibility:* The managed care operating environment expects consumers to become “partners” in health care. Member involvement includes two discrete dimensions: a greater level of self-care, behavior modification and preventive activities and member responsibility for some of the “navigation” and coordination of their health services.

*Fairness:* Members feel that all patients are treated with the same care and that medical decisions are just. Members generally talk about fairness on a global level; they not only seek fairness for themselves and their families, but feel that there should be at least a minimum threshold of care available to all people.

*Dignity/Respect:* Physicians and health plans treat patients as capable and explain conditions, treatment options and patient responsibility clearly.

*Quality:* Consumers understand and have relatively easy access to services and obtain good medical outcomes given their condition.

### ***Principles for Consumer Involvement***

The following guiding principles serve as the basis for recommendations as to how increased consumer involvement can improve the managed care system.

1. Member/patient involvement in managed care decision making, including member participation in product design, development of marketing materials and quality improvement processes will improve managed care quality and enhance consumer service and satisfaction.
2. Member/patient involvement mechanisms (such as Consumer Feedback Loops, ombuds programs, member advisory committees and member participation in policy and committee structures) should be created and employed to improve the overall efficiency of plans and medical groups.
3. Strong public and private incentives, in addition to the market-driven need to attract and retain customers are necessary to ensure that health plans and provider groups develop organized systems of consumer involvement and advocacy.

### ***Recommendations for Consumer Involvement***

1. Health plans will enhance consumer trust by formally including consumer input into policies and practices across all levels of the plan. The Task Force strongly encourages health plans and consumer groups to jointly design workable mechanisms for doing so. State government should exercise its considerable bargaining power as a health care purchaser by ensuring that members’ interests are incorporated into health plan design and operations.

*In addition, we recommend that Knox-Keene be amended to include more extensive provisions for consumer involvement in plans’ governance, policy making and operational structures. Several features of the health care market render health plans more deserving of*

state-mandated forms of governance than organizations that produce or provide other goods and services:

Health care is more personal in nature than other goods and services; decisions about health care and treatment can involve significant bodily harm and/or be life threatening. Consumer expectations for regulation in health care are higher than they are for most other goods and services.

Consumers have a compelling interest in provision for and protection of public health. Consumers are “obligatory users” of the health care system (i.e. many sick and/or pregnant consumers must use the system whether they want to or not).

Health care is characterized by imbalances in availability of information to consumers more significant than that in most other industries.

*Under Knox-Keene, HMOs are currently required to:*

- Establish a governing body which is composed of at least one third subscribers or enrollees
- Establish a standing committee which is responsible for public policy participation and whose recommendations and reports are regularly and timely reported to the board. The membership of the committee shall be at least 51% subscribers/enrollees,
- Describe the mechanism by which enrollees/subscribers can express their views on public policy matters, and
- Establish procedures to permit subscribers and enrollees to participate in establishing the public policy of the plan and incorporate these procedures into the plan’s bylaws.

*The proposed revision of these regulations would read as follows:*

- Establish a governing body which is composed of at least one third members or enrollees and ensure that sufficient resources are made available to educate enrollee board members so that they can participate effectively. Enrollee board members should neither be employees of nor have a significant financial interest in the organization or competitor organization~~and~~
- Establish a member advisory committee to ensure that members’ values and needs are integrated into the design, implementation, operations and evaluation of the plan/HMO. This committee shall communicate and advocate for members’ needs and serve as a resource for the governing body and HMO/plan administrators. It shall be responsible for establishing mechanisms and procedures for enrollees to express their views and concerns about the HMO/plan. The plan attributes/functions this committee may address include but are not limited to: benefits and coverage, member communications, quality assurance, marketing and grievance resolution.



- Describe the mechanisms and lines of accountability used for obtaining and incorporating member feedback into policies and practices across all departments/divisions.
  - Demonstrate how member feedback has been incorporated into plan policy, operations and evaluation.
2. Purchasers and employer groups, including government agencies, contracting for health care should exercise their bargaining power to encourage plans to insure that medical and other provider groups develop and utilize mechanisms of consumer feedback.
  3. Accrediting bodies should develop standards regarding plans' and provider groups' utilization of consumer feedback in policy development and implementation.
  4. The task force encourages collaborative efforts among government, foundations, plans, provider groups and purchasers to fund expansion of organized systems of consumer involvement should be encouraged.
  6. The appropriate managed care oversight agencies (currently DOC, DOI and DHS) should have member advisory committees responsible for ensuring that managed care plan members' values and needs are integrated into the collection of information from and regulation of managed care organizations.

## CONSUMER INFORMATION, COMMUNICATION&INVOLVEMENT BACKGROUND PAPER

### I. INTRODUCTION

Rapid changes in the health care delivery system have resulted in elevation of the importance of consumer information and involvement. The potential benefits of managed care, namely lower costs, higher quality of care and greater consumer satisfaction will be realized only in a system characterized by active and meaningful consumer participation. If these benefits are to be realized, consumers/patients need access to clearly communicated information relevant to decisions about appropriate treatment.

This paper explores the issues of consumer information and involvement in managed care. A discussion of effective communication of consumer information serves a bridge between the information and involvement sections to highlight the importance of the manner in and media through which information is collected and disseminated. The paper concludes with principles upon which the value of improving consumer information and involvement in health care are based, and presents recommendations for carrying these principles forward in practice.

### II. THE ROLE OF THE CONSUMER IN A MANAGED CARE SYSTEM

#### A. *Transition from Fee-for-Service to Managed Care: From “Patient” to “Consumer”*

The role of the consumers in the health care delivery system has changed dramatically with the rise of managed care. Traditionally, consumers were patients who went to their trusted doctors for treatment and either paid the bills or sent the bills to their insurance company for reimbursement. The FFS system focused on the health of the individual, and doctors were perceived as patient advocates who would ensure that necessary and appropriate care was obtained; they navigated the system for the patients and were generally not bound by fiscal constraints. Most patient-physician relationships were characterized by trust; if patients were not satisfied with a physician, they could change immediately to another doctor. Under FFS, little formal information about physicians (e.g. quality or outcomes) was available, and in the absence of mistreatment or malpractice, physician authority was generally not questioned. Consumer involvement in the insurance process was minimal and generally administrative in nature; remote third party insurers paid whatever bills consumers or their physicians submitted without authorization or utilization review processes. This option has become increasingly unaffordable.

The move from a focus on the health of the individual under FFS to the managed care system's focus on population health has had a significant impact on the consumer. The consumer is conceived as an active participant in a “system” of care rather than an individual receiving a broad range of advice from a single, trusted source. In response to this new consumer role and its accompanying responsibilities, the market has brought a great deal of information until recently considered “professional” into the public domain. Information on health and health care -- from popular media presentations on the health system to Internet databases, newsgroups and patient groups to consumer-oriented medical guides and magazine “rankings” of doctors, hospitals and

health plans – now finds its way into a large number of American homes. Publications such as *U.S. News and World Report* and *Consumer Reports*, organizations such as PBGH and a broad range of private companies have produced a great deal of consumer-focused health information. In his paper “Trust and Trustworthy Care in the Managed Care Era,” Brad Gray introduces the notion that efforts to find alternatives to dependence on the historical physician/patient trust relationship have developed in recent decades as new organizational forms have emerged in the health care delivery system. Patients now routinely seek second opinions, obtain services from “alternative” practitioners, and consume journalistic lists of “the best” physicians and hospitals.

While consumers are faced with a much broader range of health-related information, it is not clear that they are able to use much of it to educate themselves or make effective decisions. Many consumer advocates are concerned that much of the information directed at consumers is incomplete, biased and conflicting, and serves to confuse consumers rather than help them.

### ***B. Consumer Values in Health Care***

Attempts to improve upon the current level and nature of consumer information and to provide the information consumers may need to assume the new role described above effectively should be driven by an understanding of consumer values. Advocates and studies have characterized seven consumer values that relate to the health care delivery system<sup>10</sup>

*Affordability:* Quality health care at a reasonable price. Members most often cite affordability as their primary purchasing criterion and express a fear of losing access to quality care because costs are too high for their employers or themselves.

*Choice:* Consumers are allowed to choose their health care providers, ideally at each of three levels: the plan, the medical group and the physician. Consumers often feel that they do not have the information they need to make informed choices.

*Accountability:* Consumers enrolled in a plan are presented with clearly identified agents and processes through which to resolve problems. Members are concerned that accountable organization resolves problems in a pre-stated and timely manner.

*Personal Responsibility:* The managed care operating environment expects consumers to become “partners” in health care. Member involvement includes two discrete dimensions: a greater level of self-care, behavior modification and preventive activities and member responsibility for some of the “navigation” and coordination of their health services.

*Fairness:* Members feel that all patients are treated with the same care and that medical decisions are just. Members generally talk about fairness on a global level; they not only seek fairness for

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<sup>9</sup> B Gray, “Trust and Trustworthiness in Managed Care” *Health Affairs* January/February 1997.

<sup>10</sup> These values have been developed by California Health Decisions, and are described in more detail in its “Condition Critical Project” report.

themselves and their families, but feel that there should be at least a minimum threshold of care available to all people.

*Dignity/Respect:* Physicians and health plans treat patients as capable and explain conditions, treatment options and patient responsibility clearly.

*Quality:* Consumers understand and have relatively easy access to services and obtain good medical outcomes given their condition.

### ***C. The Consumer's Need for Information***

The advent of managed care and the efforts of government and employers to control costs resulted in dramatic changes in the relationships among patients, physicians and insurers and significantly impacted the needs and responsibilities of the patient. Though many argue there has always been an ethical imperative for provision of consumer information – health plans, facilities and medical professionals face an ethical obligation to inform consumers about how their actions can affect the consumer's life and health<sup>11</sup> – there is now an organizational imperative as well. Optimal functioning of the system rests on the assumption that consumers (as “partners” in their own health care) will obtain and use information on topics such as health promotion, medical treatment and insurance administration that were long the exclusive province of professionals.

Consumers dissatisfied with managed care often worry that they are unable to advocate effectively for themselves, and that physicians are no longer in a position to strictly represent their needs. The transition of the health care delivery system to a managed care focus has resulted in consumers taking on many of the responsibilities they assume when purchasing other goods and services; they must advocate for themselves, seek value and participate in their own care and treatment decisions. Proponents of managed care assert that the promise of a competitive and increasingly consumer-focused environment is that consumers will be able to choose among health plans providing a variety of value and cost propositions, and will be more satisfied for having been allowed to exercise choice. For consumers to benefit from this hypothetical scenario, however, they must have access to and an understanding of information that will allow them to assess differences among plans and providers. They must also have a choice of plans broader than that which many Californians currently enjoy.

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<sup>11</sup> Medical ethicists ground this obligation in the principle of respect for an individual's autonomy and their right to make choices about how they receive medical care. Beauchamp and Childress (1994) argue that “the obligation to respect patients' autonomy requires equipping them to overcome their sense of dependence and achieve as much control as possible or as they desire.” Sofaer (1997) makes the additional point that consumers should have a right to this information even if it is technically difficult for them to understand.

#### **D. Consumer-Focused Information**

To successfully participate in health care decision making, consumers need both basic factual information and assistance with interpretation of complex clinical information. Several recent studies have shown that today's consumers do not understand even the most basic details of their health insurance coverage. A Louis Harris/Towers Perrin survey<sup>12</sup> conducted at the end of 1995 found that: 67% of consumers did not have a good understanding of the differences between traditional fee-for-service and managed care plans; a third of consumers had never heard the term "health maintenance organization" or had heard it but did not know what it means; 55 % had never heard the term "managed care" or did not know what it means; and 77% had never heard the term "fee for service" or did not know what it means. The study found that people enrolled in managed care plans were as likely to be ignorant of managed care terms and concepts as those enrolled in fee-for-service plans.<sup>13</sup> Another recent study of the "readability" of health insurance literature and contracts found that the average document was written at the reading level of between third/fourth year college and first/second year graduate school.<sup>14</sup> The results of the 1992 Adult Literacy Survey conducted by the US Department of Education indicated that writing directed at the "general public" should be at the seventh or eighth grade level.<sup>15</sup>

Beyond understanding the basic operating assumptions of these two types of insurance, a truly informed health care consumer might be interested in a broad range of information about his/her plan and providers. When a consumer is in a position to select a plan, to choose wisely she needs access to and an explanation of the information that will help determine whether the plans meets the needs of her and her family. To be an effective (or well-informed) member, she needs information on accountability and on processes that exist should a problem arise, on incentives that might influence physician or plan choices, on "self care" and her ability to influence health outcomes and on the logistical and continuity of care implications of a change in the plan's contracts with providers.<sup>16</sup> An outline of the range of information a fully informed might want when choosing and receiving care under a health plan is presented below. This outline is presented with an important note: employers currently obtain much of this data and make decisions on behalf of their employees.

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<sup>12</sup> Louis Harris and Associates *Navigating the Changing Healthcare System Survey* 1995.

<sup>13</sup> Additional information from this survey is presented in Isaacs S, "Consumers' Information Needs: Results of a National Survey," *Health Affairs*, Winter 1996.

<sup>14</sup> Hochhauser M, letter to the Editor *Health Affairs* September/October 1997, p 220.

<sup>15</sup> Kirsch IS et al., "Adult Literacy in America, A First Look at the Results of the National Adult Literacy Survey," Washington, US Department of Education, 1993.

<sup>16</sup> Ideally, in choosing and using a plan, consumers with specific conditions would be able to receive a general standard of care protocol so that they could choose plans that best suited them. However, since there is minimal to no risk adjustment for physician compensation and ratings currently, the adverse selection created by such protocol disclosure would be too strong. This ERG group supports efforts at risk adjustment and would like disease specific information to be available once incentives can be aligned.

<sup>17</sup> "The Right to Information" draft prepared for the Subcommittee on Consumer Rights, Protections and Responsibilities of the Federal Advisory Commission on Consumer Protection and Quality in the Health Care Industry.

*Plan information:* licensure status; years in existence; provisions for confidentiality of member medical records; description of the responsibilities and functions performed by the plan in regard to specific insurance products.

Additional information about health plans that is relevant to consumer decision making and should be made available to consumers includes the plan's tax status.

*Insurance product information:* covered benefits; limits on coverage, including annual limits, lifetime limits, limits for specific conditions and policy on coverage of experimental treatments and procedures; cost-sharing mechanisms; dispute-resolution mechanisms and legal remedies; provider panel and availability; utilization review procedures; care management information; and plan performance on quality measures.

While many consumers still do not have the option to choose among a variety of competing health plans, others are faced with an increasing number of health insurance products and features. As insurance providers broaden the selection of available products to meet the demands of a competitive marketplace, consumers (and employers, who are often making the initial plan purchase decision) are faced with an increasingly complex initial product decision that will have important ramifications for subsequent choices of provider, facility and treatment options. Consumers must have clear information on the product in which they enroll if they are to use services within it effectively.

*Information on networks, including medical groups and facilities:* accreditation status; volume of procedures performed; and performance on quality measures. Relevant information about networks includes rules regarding referrals to specialty care and centers of excellence; urgent and emergency care and coverage; and rules governing and coverage implications of out-of-network services; and information about the process through which the plan and its provider networks make medical decisions.

*Information on health care professionals:* education, board certification and recertification; years of practice; experience performing certain procedures; and performance on consumer satisfaction and quality measures. Consumer information about health care professionals might also include tax status and financial relationships of a provider's practice, how the provider is compensated and the provider's institutional affiliations and referral patterns.

A truly informed consumer would thus explore a broad range of issues in choosing a plan and navigating the health care delivery system. This information is increasingly being made publicly available through both government disclosure mandates and by non-profit and private organizations. Numerous studies show, however, that consumers have the capacity to process a limited amount of information at any one time and that they rely extensively on *informal* sources of information such as family and friends to help them make many of their health-related decisions<sup>18</sup>

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<sup>18</sup> Isaacs, SL, "Consumers' Information Needs: Results of a National Survey" *Health Affairs*, Winter 1996.

<sup>19</sup>. Consumers indicate that when examining health plans, they are most interested not in standardized measures of performance but in how the plan works for “people like me.” They also indicate that they continue to consider the primary health care system relationship they have to be with the physician, not the health plan. Sources of information and “quality” measures have expanded and increased, but it is unclear how much of this information is reaching and/or being used effectively by consumers.

### **III. CONSUMER INFORMATION IN HEALTH CARE: CURRENT LAW AND PRACTICE**

The proliferation of consumer information in health care is a result of legal mandates for disclosure of information, large purchaser initiatives to provide information, private for-profit enterprises that have responded to consumer demand and the beginnings of a consumer movement. HMOs have always been required to comply with extensive disclosure mandates, but information disclosed under existing regulation has not resulted in a change in consumers’ understanding of and involvement in health plan operations over time. Large, organized purchasers such as PBGH, through surveys and initiatives like CCHRI Health Plan and Physician Value Check surveys provide much of the health plan and provider group comparative data currently available. In addition, many private sector enterprises have formed to fill the information gap.

As mentioned earlier, individual consumers have not wielded much power in the health care delivery system except when they have had their interests represented by large employers or purchasing coalitions. While some consumers with special needs have recognized this problem and banded together with others with common health needs or disease states to form what have become fairly powerful lobbies, there has been no “general” consumer movement pressuring the health care delivery system, and efforts to encourage one would likely be confounded by the diversity of health care related interests in the general population.

#### **A. Current Industry Practice: Information Collection and Dissemination**

##### *Government*

The public sector, through the California Office of Statewide Planning and Development (OSHPD) and the Federal Employee Health Benefit Program (FEHBP) collects a range of information from the different components of the health care delivery system. OSHPD collects financial and utilization data from plans both on the general plan population and for specific health conditions. Some of this data is available through the Internet, though data available through this forum is often insufficient for statistically significant analysis. FEHPB collects customer satisfaction, choice and access data annually. Both the FEHBP and HCFA have agreed

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<sup>19</sup> Edgman-Levitan, S and Cleary, PD, “What Information Do Consumers Want and Need?” *Health Affairs*, Winter 1996.

to test the FACCT measures described on pages 13-14 of this document as part of an attempt to provide information that is relevant to consumers.

To date, state regulation regarding information has predominantly required identification of doctors in plans, a review of their credentials, and basic information on how medical groups are compensated. Complaints about California's public system of information access and provision have asserted that information is not complete, standardized or up-to-date, that certain information is not released to the public, and that information is often not easily accessible. In a 1992 study, the California Auditor General found that the DOC had been lax about maintaining its public access files, responding to complaints and performing required monitoring visits.<sup>20</sup>

In a 1996 report, Consumers Union documented the difficulties consumers have in obtaining information from the Department of Corporations.<sup>21</sup> The report indicated that health plan surveys are not issued in a timely manner and do not contain information which is useful to consumers. Since the report was issued, there has been some improvement in the adequacy and frequency of the surveys, according to the Consumers Union. Nevertheless, it remains extremely difficult for consumers to get helpful information from the DOC. Although the Knox-Keene Act requires the DOC to educate and inform consumers about HMOs,<sup>22</sup> this report indicated that DOC provides consumers with little information to assist them in choosing or using a health plan. Current law requires the DOC to make summaries of surveys available to consumers, but a Consumers Union survey revealed that only the most assertive consumers are able to obtain even this information.<sup>23</sup> The DOC also publishes a report on consumer complaints pursuant to a statutory mandate. This report details the number and type of grievances filed with the DOC for each health plan in the state. It is difficult for consumers to use this information in evaluating a health plan, however, because this report does not indicate the severity or validity of the complaints or if any action was taken by the Department or the plan in response to the complaint. (See the Task Force Dispute Resolution paper for a further discussion of this issue.)

#### *Private Sector Organizations*

A range of private non-profit and for-profit organizations such as independent quality monitors, purchasing coalitions, consumer advocacy groups and individual employers have recognized the consumers' need for information and has used purchasing power or potential media influence to demand and publicize plan information. A significant amount of plan-level information has been gathered and made available through the National Committee on Quality Assurance (NCQA) accreditation process and Health Plan Employer Data and Information Set (HEDIS) initiative. NCQA currently publishes a report called the "Quality Compass" which presents comparative HEDIS scores and accreditation information for 250 health plans. As the industry matures, more

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<sup>20</sup> "HMO Consumers at Risk: States to the Rescue," (Washington: Families USA, July 1996), p. 16.

<sup>21</sup> Hamburger E, "A Shot in the Dark: The Department of Corporations Fails in its Job to Educate and Inform Consumers about Choosing an HMO," Consumers Union of the US, Inc., West Coast Regional Office, April, 1996.

<sup>22</sup> California Health and Safety Code 1342(b) (West 1996).

<sup>23</sup> 1997 survey by Consumer's Union West Coast Regional Office (unpublished)



data becomes available and measures are refined, these surveys and reports are modified. HEDIS has come under criticism for focusing too heavily on prevention and utilization measures and failing to devote sufficient attention to treatment of chronic and acute diseases. Recent efforts have focused on development and publishing of meaningful outcomes measures. The other major criticisms of this data source are that plans are not required to participate in and publish HEDIS results and that the data are “self-reported,” and are thus not as reliable as independently collected data. While the California Cooperative Healthcare Reporting Initiative (CCHRI) publishes independently audited HEDIS information for the 22 health plans covering 95% of the commercially enrolled California population, there are at least 24 additional HMOs in the state for whom this information is not available.

Under the HEDIS programs, plans compare themselves to health promotion and disease prevention targets established by the U.S. Public Health Service, under the “Healthy People 2000 Initiative.” HEDIS presents measures that are designed to be meaningful to both employers and consumers in the following areas:

- *quality of care*, with measures including preventive services, prenatal care, acute and chronic illness and mental health
- *member access and satisfaction* which presents such “access” measures as waiting time for appointments, general medical care and mental health care and “satisfaction” as the percent of members who indicate that they are “satisfied or highly satisfied” with the plan and the percent who indicate that they would renew their membership
- *membership and utilization* data include enrollment by age, gender and payer, disenrollment data, high occurrence/high cost DRGs, frequency of selected procedures, inpatient and ambulatory bed/days, discharges and average length of stay, births and average maternity length of stay, inpatient and outpatient mental health utilization, inpatient and outpatient chemical dependency utilization and outpatient drug utilization and cost
- *finance* information, including cost per member per month, premium per member per month, medical loss ratio, administrative loss ratio, and indicators of financial stability, and
- *health plan management* including percent of board certified primary care physicians and specialists, basic information on physician turnover and physician compensation, and information on initiatives such as case management and utilization management programs

The Foundation for Accountability (FACCT) is a not for profit coalition dedicated to helping consumers make better health care decisions. FACCT’s board of trustees is made up of consumer organizations, corporate health care purchasers and government purchasers representing 80 million Americans. FACCT has released measures that attempt to create a relevant, comprehensive picture of quality of care for *specific conditions* – like asthma or diabetes, *lifestages* – like pediatrics or end of life, and *population status* – like health status over 65 or health risk behaviors. FACCT creates comparative information by organizing and weighting data from HEDIS, FACCT measurement sets, the Agency for Health Care Policy and Research’s CAHPS,

the Joint Commission on Accreditation of Health Care Organizations' ORYX and public health databases.

Most information, including HEDIS and FACCT, is collected at the plan (rather than the medical group or physician) level. In response to the fact that consumers are interested in physician-level information, PBGH and The Medical Quality Commission, recently undertook the "Physician Value Check," based on interviews with 58,000 consumers which produced rankings of 58 physician groups on a series of patient satisfaction and quality measures. The study reviewed physician practice group performance on such factors as overall patient satisfaction, ease of getting referrals, and their record of keeping blood pressure and cholesterol under control and counseling patients on preventive care.

For additional information on the main public and private providers of quality and outcomes data and accreditation, see *Task Force Attachment 1: Quality Measures and Accreditation*.

Consumer advocacy groups and private individuals and entities use a combination of publicly-generated and market-generated information to provide consumers with health care system information and various types of "rankings," generally at the health plan level. Publications such as Consumer Checkbook's "Consumers' Guide to Health Plans," Newsweek Magazine, Bloomberg Personal and US News and World Reports "Guide to HMOs" select basic measures of health plan performance and rank plans accordingly. Numerous "how to" guides counsel consumers on selecting plans and providers, navigating the health care delivery system and effectively advocating for themselves and their families. More recent developments include a broad range of Internet sites which are designed to help consumers gain information and educate themselves through a broad range of applications. Several sites allow consumers to sort plans and providers according to their own prioritization of factors such as quality, cost and location (using available data from NCQA and other sources); other sites provide access to consumer-focused publications on management and treatment of common health conditions (using publications produced by organizations like the AHCPR and medical trade organizations); and a broad range of sites provide "ask the doctor or nurse" question and answer forums for consumers. As stated earlier, these information sources present data not previously accessible to consumers, but because of they are produced and disseminated by independent organizations operating without an agreed-upon set of standards or a regulatory framework, they offer often-conflicting, necessarily biased opinions.

The developers of these publications and applications face many of the challenges described earlier: individual consumers are interested in different features of plans and networks; information is rarely collected in a consistent enough format to allow for true comparability; and little consensus exists around how to validate quality or outcomes measures to ensure that information collection methodologies are not biased toward the measures.

Because there is little consensus on what information or measures are the "right" ones to collect and disseminate, it is instructive to examine what is becoming "customary" in the industry. A nationwide study of several large employers, health plans, purchasing groups and consumer advocacy organizations (including CalPERS, PBGH, Kaiser Permanente of Northern California the Managed Risk Medical Insurance Board, Medi-Cal, Health Choice, Inc. and the California

Health Information Counseling and Assistance Program in the state of California) focused on what measures organizations use to present consumers' ratings of care in FFS and HMO plans.<sup>24</sup>

The most commonly reported survey-based performance measures in the categories of "customer satisfaction," "process measures" and "method of communication" follow:

*Customer Satisfaction*

- Satisfaction with waiting time for an appointment and in the physician's office
- Satisfaction with access to care
- Satisfaction with personal treatment during physician services
- Overall satisfaction with the provider
- Overall satisfaction with health care
- Satisfaction with the range of services covered

*Process Measures*

- Percent of children immunized
- Percent of women who received a mammogram
- Percent of adults who had their cholesterol level checked

*Modes of Communication*

Findings in this category include:

- Consumers prefer personal communication of information (e.g. counseling sessions), because they find feedback on their personal health insurance situation more useful than general information
- Consumers prefer information in print so that they can take it home and share it with their families; "report cards" are the most popular format for conveying information in print
- Live presentations are most effective when plans are working with low literacy populations
- Most plans have not tested their informational materials with consumers. Those planning to test materials indicated that they would use focus groups and limited cognitive testing.

**B. Cost/Benefit of Information Collection**

Efforts to increase the amount and quality of consumer-focused information collected must take into account the cost of data collection relative to the benefit associated with additional information. As information systems make it easier to collect and process enrollment, encounter and survey data, it is important to understand what information is actually considered relevant by consumers, to ensure that money spent on collection, production and dissemination of some types of information helps achieve the end of producing useful information. Collection of a considerable amount of information about the health care delivery system, though technically feasible, can be both very costly and of marginal value to the average consumer.

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<sup>24</sup> Research Triangle Institute, "Information Needs for Consumer Choice Case Study Report," Report prepared for the Office of Research and Demonstrations, HCFA (Research Triangle Park, NC: RTI, 1995).

The California HMOs serving PBGH members created CCHRI to provide ~~un~~ audited data on HEDIS quality measures. The study covers approximately 11 measures of quality for 22 plans. The out-of-pocket costs for CCHRI are approximately \$2 million per year; the costs borne by health plans and providers to comply, supply data and answer inquiries come to at least another \$2 million. PBGH surveyed 58,000 managed care consumers receiving care from 58 different medical groups in California to assess satisfaction and perceptions of quality. The cost to PBGH and other study sponsors was approximately \$700,000<sup>25</sup>.

### **C. Standardization of Information**

Standardization of survey sampling methods, data collection modes, survey questions, and analytic methods is necessary if comparisons of health plans are to be useful. This level of standardization requires a significant financial commitment as well as cooperation from the plans. Where there is standardization currently, it is generally at the local or purchasing organization level.

Commitment of public agencies will be necessary to achieve a level of standardization which would allow for meaningful comparisons of plans. The Consumer Assessment of Health Plans Study (CAHPS), funded by AHCPR, is currently developing and testing methods for measuring consumers' satisfaction with their health plan and ways to communicate the results to consumers.<sup>26</sup>

## **IV. PRINCIPLES AND RECOMMENDATIONS FOR DEVELOPMENT OF EFFECTIVE CONSUMER INFORMATION**

### ***A. Principles for Consumer Information***

The following principles should guide development of recommendations regarding consumer information in health care:

6. Full and accurate disclosure of appropriate information can serve to foster best practices
7. Consumers' ability to understand differences in quality among health plans and providers is critically important to efficient functioning of the health care delivery system
8. Consumers' ability to choose among and effectively use health plans and providers is critically important to efficient functioning of the health care delivery system
9. Consumers should have unbiased, standardized information about health plans, medical groups and physicians
10. Dissemination of accurate, useful information will enhance consumer trust in the managed care system and drive quality improvement by plans and providers

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<sup>25</sup> PBGH/Medical Quality Commission, Physician Value Check Survey.

<sup>26</sup> HCFR Fall '96, p. 29.

***B. Recommendations for Consumer Information***

9. The appropriate state managed care oversight organization (currently the DOC) should issue a request for proposals for production of a consumer-focused, educational booklet on the managed care system in California. This publication should be produced by an organization with experience in health benefits purchasing and communication. It should be produced at a simple enough reading level and in sufficient formats and languages so that it is useful to all consumers. The publication should be tested and evaluated with consumers to determine that it is understood by and useful to consumers. When data support that the publication is useful and understood, a dissemination plan should be developed to ensure that it is distributed to all managed care consumers.
10. The appropriate state managed care oversight organization (currently the DOC) should create and update at least annually a “standard product description” in a format to facilitate direct comparison of plans by consumers, designed with input from stakeholders, in as non-political a process as possible. The CalPERS format should be considered as a model for this document. DOC should require plans to use the standard format to present information about any product they offer. This standard benefit characteristics document should include a statement on how drug formulary decisions are made, key elements of the plan’s grievance procedure (including a description of any arbitration processes), “exit polling” information on number disenrolling and primary reasons for disenrollment and, for each plan or medical group with which the plan contracts, a brief but specific description of the referral and authorization process and the process through which medical decisions are made. The DOC should make these descriptions available to consumers upon request free of charge and should make this information available on the Internet.
11. Plans should be required to submit to the appropriate state managed care oversight organization information on approximately 10 major health conditions or illnesses requiring referrals to specialty centers or centers of excellence (e.g. bone marrow transplants, coronary artery bypass grafts). Data should be reported on an annual basis for the prior year, and should include, for each condition or procedure, where and from whom the patient received care, and how many of the procedure in question the center to which the patient was sent performed in that year.
12. Upon request by an enrollee all plans and medical groups should be required to provide copies of any written treatment guidelines or authorization criteria.
13. The appropriate state managed care oversight organization (currently DOC) should cause to be created a “Super Directory” of physicians and other primary care providers (e.g. advanced practice nurses), hospitals, clinics and medical groups participating in health plans, indicating which plans or groups they contract with. The purpose of this directory is to ensure that consumers receive accurate information on whether a particular provider or group will be available to him/her as a member of the plan. Primary care physicians’ entries should indicate whether or not they are accepting new patients and to what facilities or specialists their patients may be referred. Plans should be required to update this information on the Internet continuously, and to update and make it available in print at specified locations at least quarterly. This information could then be made available to consumers through employee

benefits offices, libraries and consumer advocacy and assistance organizations. Plans should be required, upon member or potential enrollee request by telephone to provide “Super Directory” information, i.e. to indicate whether a particular physician or provider group is a member of the plan’s network, and whether each participating primary care physician is accepting new patients.

14. The appropriate state managed care oversight organization’s (currently DOC’s) report on grievances should be expanded to include more detailed and meaningful information on grievances, including severity and validity of the complaint and enforcement of action taken as a result of the complaint. See the Task Force Dispute Resolution paper for specifics
15. The appropriate state managed care oversight organization should support and fund, to the extent possible in collaboration with private sector efforts, gathering of additional patient satisfaction and quality data at the provider group level as well as the plan level. The PBGH/Medical Quality Commission “Physician Value Check” study is a good model to use as a starting point for medical groups, and the FACCT framework is one example of a good model for collection of data at the plan level.
16. Employers that pay a portion of employees’ health benefits coverage should include such payments as a separate line item on employee pay stubs to begin to increase awareness that dollars spent on health benefits are a part of employees’ total compensation. Employers should be encouraged to collect information from their employees on their experiences and problems with health plans and medical groups so that this information can be used in the plan negotiation process.

## V. EFFECTIVE COMMUNICATION OF CONSUMER INFORMATION

Mandating or encouraging provision of information to consumers will not ensure that consumers have the ability to act on the information. Information must be both relevant and comprehensible to consumers. In considering how health care information should be presented, one must consider several factors: if information is to be useful to consumers, it must be presented in an accessible language and medium; it should be presented with an understanding of the target audience; and it should be easily accessible and current. The consumer’s trust of and perception of the credibility of the party presenting the information is extremely important to his/her receptivity to it.

Because health care consumers are extremely diverse in health status, educational background and interest, selection of a relevant, meaningful subset of information to make available to consumers has proven extremely difficult. Several studies have been conducted, however, that attempt to offer insight into how consumers make health insurance decisions.<sup>27</sup>

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<sup>27</sup> Andrews, R., Curbow, B. Owen, E. and Burke, A.: “The Effects of Method of Presenting Health Plan Information on HMO Enrollment by Medicaid Beneficiaries” *Health Services Research* 24 (3):311-327, August 1989.  
Sofaer, S., Kenney, E. and Davidson, B.: “The Effect of the Illness Episode Approach on Medicare Beneficiaries’ Health Insurance Decisions.” *Health Services Research*, 1992.

### **A. Current Law/Practice**

The DOC regulates both the format in which plan information presented and the content of marketing materials. Public and private sector health care purchasers, advocates and plans, however, use a wide variety of approaches and media to communicate plan information. The state mandates that marketing material not be “untrue, misleading or deceptive.” If a plan’s materials are deemed unacceptable by these measures, the plan is required to publish a correction or retraction in the same medium. Additionally, plans must have marketing/enrollment literature that uses a “disclosure form” or have “materials containing information consumers need to select a health plan and use it effectively.” This material must be presented in readily understood language and in a clearly organized form. Premium prices must be stated exactly.

In practice, health plans, purchasers and advocacy groups use a wide range of communication styles for marketing, consumer satisfaction data, process and outcomes measures, and general plan information. Media approaches to dissemination of this information by plans and independent agencies range from print, radio and television to telephone hot-lines and Internet sites. While some groups introduce and explain performance measures, many do not, reinforcing research findings that people often do not understand the managed care context and what various performance measures mean. Measures of consumer feedback mechanisms and relative consumer ability to “navigate” the plan are generally not included.

Non-profit and private sector organizations have made significant attempts to present information about managed care and the health care system to consumers in relevant, understandable language and terms. Organizations from the AARP *65 News and World Report* to numerous small consumer advocacy organizations are interpreting and “packaging” information on health plan quality and cost and are disseminating reports through print publications and the Internet. While these efforts succeed in bringing information to consumers who would otherwise not get it, they are often criticized for increasing consumer confusion by failing to use consistent measures and presentation of data.

## **VI. CONSUMER INVOLVEMENT IN THE HEALTH CARE SYSTEM**

Although many experts agree that better information access and communication will benefit consumers and enhance educated choice, most feel that consumers will not be able to remedy problems they encounter in the health care delivery system without organized mechanisms of consumer involvement and advocacy. The health care delivery system in the era of managed care has become sufficiently complex to confound even the most educated and involved members. In his article, “Consumer Protection and Managed Care: The Need for Organized Consumers,” Marc Rodwin makes the case that formal, organized consumer advocacy is necessary given the current



organizational dynamics of the American health care system.<sup>28</sup> Rodwin and other advocates of enhanced consumer involvement assert that formal consumer involvement tools and mechanisms are necessary to ensure that the consumer, once informed, has a “voice” in the health delivery system. The major difficulty is not with the amount or quality of data available, but that consumers lack resources and must deal with their problems as individuals.<sup>29</sup> This problem is compounded by several industry factors: individual members most often do not control the funds for purchasing the services they receive; many consumers who receive health insurance through employment do not have a choice of plans, and thus are forced to be dependent on a health plan which they do not have the option of leaving if they are not satisfied; individual consumers tend not to become involved in negotiations with their health plans until they have a problem, at which point – often facing the physical limitations, stress and cost of serious illness – they must be able to provide significant, detailed evidence of wrongdoing on the part of the plan.<sup>30</sup> Finally, health plans and medical groups, in contrast to the vast majority of consumers, often have fiscal incentives and sufficient resources to address their interests proactively.

#### ***A. Current Law/Practice***

While most health plans have some member involvement mechanisms in place (requirements under Knox-Keene regulations are enumerated on page 16 of this document), few have implemented extensive programs in this area. Most consumer activity has focused on issues such as review of marketing materials and grievance procedure policy development. Most plans acknowledge that while they attempt to obtain member input on print materials, they do very little formal testing of educational and marketing materials to determine whether consumers understand or can effectively use them.

Some purchasers and plans have begun to adopt tools such as the “Consumer Feedback Loop”<sup>31</sup> to allow all parties in the system to obtain and benefit from the input of members. While purchasers, plans, providers and consumers have all recognized the benefits of such involvement mechanisms, strong incentives will likely be necessary if plans and providers are to seek active participation of members in formulation of policies, marketing materials, product design and plan operations and evaluation.

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<sup>28</sup> Rodwin MA, “Consumer Protection and Managed Care: The Need for Organized Consumer Health Affairs Vol. 15, No. 3, Fall 1996, pp. 110-123.

<sup>29</sup> Ibid., p. 113.

<sup>30</sup> To appeal to the plan effectively, consumers must “know that they have been denied a service or received poor quality of care, believe that the plan has acted improperly, be hopeful that filing a grievance may provide a remedy, have the time and resources to pursue the matter, and think it worth the cost of doing so. (Handler in Rodwin)

<sup>31</sup> The Consumer Feedback Loop, a tool developed by California Health Decisions, is a model for improving health care quality that involves patients, providers, purchasers and health plans in a consumer-driven process of research, solutions, change and evaluation. The Consumer Feedback Loop is a process that fosters cooperative efforts towards quality improvement. Its goal is to shape change in a health care delivery system or structure around the best interests of the consumer.



Consumer involvement currently takes on many forms: consumer advocacy groups petition governments and health plans to address their constituencies' needs; and consumers become involved in process and policy discussions at the plan and medical group level through participation in member advisory committees and ombuds programs. Though purchasing coalitions might also require that plans employ member involvement mechanisms if they wish to be included in the coalition, the major California coalitions have not yet done so.

Examples of active consumer involvement mechanisms in California health plans include one plan which has included enrollees on its board of directors and has a very active member advisory committee and the plans participating in the MediCal managed care "two plan" model, which are required to meet member involvement criteria.

### ***Recommendations for Consumer Involvement***

7. Health plans will enhance consumer trust by formally including consumer input into policies and practices across all levels of the plan. The Task Force strongly encourages health plans and consumer groups to jointly design workable mechanisms for doing so. State government should exercise its considerable bargaining power as a health care purchaser by ensuring that members' interests are incorporated into health plan design and operations.

*In addition, we recommend that Knox-Keene be amended to include more extensive provisions for consumer involvement in managed care plans, including involvement in plans' governance structures.* Several features of the health care market render health plans more deserving of state-mandated forms of governance than organizations that produce or provide other goods and services:

Health care is more personal in nature than other goods and services; decisions about health care and treatment can involve significant bodily harm and/or be life threatening. Consumer expectations for regulation in health care are higher than they are for most other goods and services.

Consumers have a compelling interest in provision for and protection of public health.

Consumers are "obligatory users" of the health care system.

Health care is characterized by information asymmetries considerably more significant than those in most other industries.

*Under Knox-Keene, HMOs are currently required to:*

- Establish a governing body which is composed of at least one third subscribers or enrollees
- Establish a standing committee which is responsible for public policy participation and whose recommendations and reports are regularly and timely reported to the board. The membership of the committee shall be at least 51% subscribers/enrollees,
- Describe the mechanism by which enrollees/subscribers can express their views on public policy matters, and

- Establish procedures to permit subscribers and enrollees to participate in establishing the public policy of the plan and incorporate these procedures into the plan's bylaws.

*The proposed revision of these regulations would read as follows:*

- Establish a governing body which is composed of at least one third members or enrollees and ensure that sufficient resources are made available to educate enrollee board members so that they can participate effectively. Enrollee board members should neither be employees of nor have a significant financial interest in the organization or competitor organization~~and~~
  - Establish a member advisory committee to ensure that members' values and needs are integrated into the design, implementation, operations and evaluation of the plan/HMO. This committee shall communicate and advocate for members' needs and serve as a resource for the governing body and HMO/plan administrators. It shall be responsible for establishing mechanisms and procedures for enrollees to express their views and concerns about the HMO/plan. The plan attributes/functions this committee may address include but are not limited to: benefits and coverage, member communications, quality assurance, marketing and grievance resolution.
  - Describe the mechanisms and lines of accountability used for obtaining and incorporating member feedback into policies and practices across all departments/divisions.
  - Demonstrate how member feedback has been incorporated into plan policy, operations and evaluation.
8. Purchasers and employer groups, including government agencies, contracting for health care should exercise their bargaining power to encourage plans to insure that medical and other provider groups develop and utilize mechanisms of consumer feedback.
  9. Accrediting bodies should develop standards regarding plans' and provider groups' utilization of consumer feedback in policy development and implementation.
  10. The task force encourages collaborative efforts among government, foundations, plans, provider groups and purchasers to fund expansion of organized systems of consumer involvement should be encouraged.

The appropriate managed care oversight agencies (currently DOC, DOI and DHS) should have member advisory committees responsible for ensuring that managed care plan members' values and needs are integrated into the collection of information from and regulation of managed care organizations.